

**STRONGER THAN EVER: A NARRATIVE AND PHOTOGRAPHIC PROJECT  
OF YOUNG ADULT CANCER SURVIVORS IN THE COLUMBUS, OHIO  
COMMUNITY**

by

Heidi Liou

A thesis submitted to the Faculty of The Ohio State University in partial fulfillment of the requirements for the degree of Bachelor of Science in Fashion & Retail Studies with Honors Research Distinction.

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## ABSTRACT

*Stronger Than Ever* is a narrative and photographic research project combining stories, inspirational quotes, and photographic portraits of young adult cancer survivors in The Ohio State University community. Young adults, a largely underrepresented group in the battle with cancer, account for 72,000 new cancer diagnoses each year (Stupid Cancer, 2013). My research plan was to interview a sample of Ohio State students and young adults in the Columbus area, concerning their experience in being diagnosed, treated, and surviving various forms of cancer. The goal was to raise awareness within my own generation that cancer can strike at any age and that the likelihood of beating the disease is becoming more frequent as understanding, effective treatment and research funding increase. Through open-ended, candid interviews, the perspectives and narrative experiences (stories) of OSU young adults who have survived cancer have been collected, analyzed, and shared. The hope is that those who read the narratives, see the portraits, and listen to the testimonies in venues like Facebook, the *Lantern*, and other related social and academic forums might become better informed about cancer as a disease and more sympathetic in their support for the cause.

## **Chapter 1**

### **INTRODUCTION**

#### **1.1 Cancer Journey**

This project is focused on cancer survivors' stories during and after their fight. Most projects focus on how to improve the livelihood of patients by improving treatment or enhancing their experience. 'Stronger than Ever' is focused on the psychological standpoint from those surrounding the patient. Getting the patient's point of view on how others are/should treat them might improve their healing process, while making them more approachable/easier to connect to from their friends and family side. The increase in knowledge about the specifics patients have to deal with on a daily basis will allow others a better approach on how to communicate with them.

The survivors sharing their stories can provide recently diagnosed individuals knowledge on what ways others used to cope with their struggles. New cancer patients are facing the biggest fight of their life, but this project can lessen the blow by providing ideas of how others have faced their own respective fight. This project can act a blueprint on how to better approach the onslaught of family and friends trying to cope with the diagnosis as much as the patient. Instead of a physical paper brochure, the internet portion of the project can act as an ever-growing, expanding brochure for patients and supporting team alike.

## **1.2 Giving Hope**

We must stand up to cancer and celebrate with cancer survivors whose stories will give hope to current cancer patients, letting them know that cancer can be overcome. The stories and photographs of young adult cancer survivors in the OSU community can speak volumes, giving hope, and spreading awareness of the story of cancer. By sharing the stories not only through traditional research venues but, importantly, through online social networks, I hope to inspire others to begin new conversations about cancer survival and create a strong community of support for young adult cancer patients in Columbus and beyond.



## **Chapter 2**

### **LITERATURE REVIEW**

#### **2.1 Scientific Background & Literature Review**

Over the last three decades, interest has increased in using a narrative approach to explore the lived experiences of people who have survived cancer (Charon, 2008; Duran, 2013; Frank, 1997; Martean, 2013; Plumer, 1995; Wells, 2013). By sharing storied experiences, recently diagnosed cancer patients have a better knowledge of what to expect. Through a narrative synthesis involving 2087 childhood cancer survivors, Duran (2013) asserts it is evident that “illness becomes our best teacher to get to know ourselves at a deeper level and the world in a new dimension with new meaning. Working through an illness brings out our best, teaching us what life is all about” (P. 179). For young adult cancer survivors (many of whom participate in digital social networking) establishing and engaging with a strong survivorship community has utmost importance for mental and physical well-being.

A common interest and commitment to eliciting, telling and listening to stories can form the core of these survivors’ communities. A review of such forums of survivor stories reveals narrative motives ranging from common health problems and questions, to plans for the future in a post cancer life. Knowing that others are interested, listening, sharing, caring about their experiences allows cancer survivors a sense of agency and hope. Narrative inquiry (eliciting, generating, analyzing, and offering experiential storied data) has the capacity to resonate with and inform both academic as well as wide-ranging public stakeholders. This narrative research project, situated on the OSU Campus and in the Columbus Community, has the potential to illuminate, for community, family, friends, for health professionals and funding agencies, the kind of lived experiences that bring

relevance and purposive action to the continuing need to understand and support the myriad needs in cancer care.

## Chapter 3

### OVERVIEW

#### 3.1 Inspiration

*“By sharing our story, our love story, something beautiful has begun to grow out of something so horrible and unfair. If we don't share our experiences how can we learn, grow and survive?”* Angelo Merendino

The story of cancer, usually kept private, is one that comes suddenly and unexpected. Recently, I had a close friend lose her mother to breast cancer. I did not know what to do or say, so I ended up not acting at all. I was too nervous to ask, even though the curiosity and care were genuine. I was afraid of upsetting her. This fear made me an idle bystander. I regret this. I regret being inactive and helpless. I wish I had been brave enough to broach the topic of cancer in a positive, supportive way with my friend. Later on, when reading about cancer, I was shocked to learn of the stories on the Internet, of how people were both directly and indirectly affected by it. Something inside of me changed that day and I decided that I should not remain oblivious, unable to provide support and removed. I realized also, through my experience and readings, that there are others who feel ineffective, the way I do--awkward and unsure about how to approach, be there and help. When I told my friend who had lost her mother about my plans to get involved, to get informed by supporting the cause for the cancer cure, she said “If there’s anyone that can be bold enough to interview a cancer survivor, it’s you!” I have taken these words as encouragement. I am now finding the courage and creating the ways to help others, both cancer survivors and those who want to help with the cancer cause. It is my hope to spread awareness and understanding, to lessen the fear people feel when confronted with illness, and the hesitation and doubt that people feel when they want so

strongly to provide support.

*Stronger Than Ever* is a narrative and photographic research project combining stories, inspirational quotes, and photographic portraits of young adult cancer survivors in The Ohio State University community. Young adults, a largely underrepresented group in the battle with cancer, account for 72,000 new cancer diagnoses each year (Stupid Cancer, 2013). Young adult survivors have a small presence in research, and knowledge of cancer survivors in this age group is scarce (Hauken et. al, 2013). My research plan was to interview approximately 7-12 Ohio State students and young adults in the Columbus area, concerning their experience in being diagnosed, treated, and surviving various forms of cancer. The goal was to raise awareness within my own generation that cancer can strike at any age and that the likelihood of beating the disease is becoming more frequent as understanding, effective treatment and research funding increase. Through open-ended, candid interviews, the perspectives and narrative experiences (stories) of young adults who have survived cancer have been collected, analyzed, and shared. The hope is that those who read the narratives, see the portraits, and listen to the testimonies in venues like Facebook, the *Lantern*, and other related social network forums might become better informed about cancer as a disease and more sympathetic in their support for the cause.

### **3.2 Problem Statement**

In difficult times during cancer diagnosis and treatment, family and close friends often do not know how to interact with and support the cancer patient. This project is beneficial for friends and family of newly diagnosed patients, so that they might be more fully and sensitively supportive without the fear of saying or doing something wrong. By collaborating with Pelotonia's marketing/PR team, various OSU student organizations, and attending events in Columbus that raise funds for cancer research, I have identified

cancer survivors and created relationships where I can enlist young adults to share their experience in audio-recorded interviews.

The stories and photographs of young adult cancer survivors in the OSU community can speak volumes, giving hope, and spreading awareness of the story of cancer. Interview participants were enlisted through professional networking strategies offered by my mentors, Dr. Candace Stout, whose work focuses on narrative research and qualitative research methodology, and Dr. Jay Kandampully. The recruitment process was transpired through word of mouth. By collaborating with Pelotonia's marketing/PR team, OSU student organizations, and attending cancer awareness events in the Columbus area, such as Pelotonia, Relay For Life, and the Step Up for Stefanie 5k Run, we had a platform to recruit participants. We were published in The Lantern, OSU's on-campus newspaper (print audience of 30,000) and provided our e-mail addresses so that people were able to reach out to volunteer as a participant.

### **3.3 Outreach**

Having learned about the project through the recruitment materials, participants contacted the researchers on a one-on-one basis--person to person or via e-mail. No one else was present during the contact discussion and no one else was present during the one-on-one interview. Participants had the choice to use their own name or to choose a pseudonym. They also had the choice to have their photograph taken to accompany the interview or not to have it taken.

The face-to-face, audio-recorded interviews and photoshoots where participants, in the most positive manner, shared their experiences with cancer, their treatment and healing, their stories about family and friends' support, and how they have become "stronger than ever" from the journey, will open the eyes of the general public to the cancer survivors that are on OSU's campus. With the permission of the participants, the

stories have been widely shared online through venues like a Tumblr blog, Twitter account, and Facebook page, which allow viewers to directly engage in conversations to bring about cancer awareness.

### **3. 4 Purpose**

The goal is to raise awareness within my own generation that cancer can strike at any age and that the likelihood of beating the disease is becoming more frequent as effective treatment and research funding increase. By focusing the narrative research on young adults within the Columbus community, I have created and encourage knowledge, understanding, and empathy about cancer survival and support.

The hope is that those who read the narratives, see the portraits, and listen to the testimonies in venues like Facebook, *The Lantern*, and other related social network forums might become better informed about cancer as a disease and more sympathetic in their support for the cause. Collecting and sharing research participants' stories of cancer survival through social media as well as through academic forums will strengthen both understanding and support of cancer research at The Ohio State University.

### **3. 5 Research Objectives**

1) To provide audiences of researchers (as well as medical practitioners, care-givers, and those involved at more personal levels) with a body of complex qualitative information and insights that are relational, temporal, and continuous, understandings that emanate directly from research participants themselves. This kind of personal experience data does not replace scientific data. It complements that data leading to more informed decisions about improving a wide range of capacities, ranging from diagnosis to cure, from personal coping with illness to interaction with family, friends, and care-givers. This research elicits, collects, and offers stories of recovery that will act rhetorically,

voicing perspectives, and potentially influencing and affecting others' perspectives of the detailed dynamics and potential in experiences of recovery. The hope is to engender the readers' understanding, care, and ultimately empathic awareness of the complexities of experience that comprise cancer survival.

2) To provide research participants, that is, narrators, an opportunity to remember, select, prioritize, thus analyzing, interpreting and evaluating experience emanating from within themselves as well as from influences outside.

3) To afford a reciprocal relationship among researcher and research participants, thus offering a partnership that values the meaning that research participants invest in their experiences.

4) To provide data that contributes to on-going research and discovery in cancer research.

## **Chapter 4**

### **METHODS**

#### **4.1 Methodology**

I had strong support from my mentor, Dr. Candace Stout, Professor of Arts Administration, Education & Policy. Dr. Stout teaches graduate qualitative research courses as well as a methodology course focused specifically on narrative inquiry. She mentored my research strategies, from locating the research participants, through creating narrative interview questions, analyzing the data, and writing up the results. She also sponsored the ways that I can continue to share my research results through conferences, the Denman Research Forum, and publications.

I set up photoshoots and multiple face-to-face, audio-recorded interviews, asking participants to share experiences about their battle with cancer and how they have become empowered from the journey. I found an equal ratio of men and women, to get a diverse view of individuals affected by cancer. I was open to interviewing anyone who was willing to share their story with me. Each research participant had the opportunity to have their photograph taken to be included in the project. Photographs of research participants were strictly voluntary.

The photographs I took of the survivor made each story more personable, connecting the story to a face. By utilizing my photography skills to capture the life and beauty of the young adult cancer survivors, I was able to engage people to read the stories of the survivors. Narrative projects (because there is so much data) require a small sample size. I had 9 participants- men and women with multicultural perspectives. I asked them for specific examples, stories, words and events that helped them stay strong.

#### **4.2 Qualitative Research**



The focus of qualitative phenomenological studies is on the research participants' accounts and interpretations of their own experience. There are no "interventions." The only "interactions" will consist of the researcher engaging research participants in open-ended interviews in a setting of the research participant's choice. Given that this is a qualitative research design, the focus is on human response to researcher interview questions. There are no "experimental" activities in this research process. Spread sheets are not a part of this narrative study. Questions posed to research participants focus on natural contexts of lived experience versus controlled environments. Data are verbal and non-numeric. The research design is non-experimental. Research interviews are open-ended and resulting data are audio-recorded verbal responses forming narratives or stories. The one-hour interviews were conducted in the location of each research participant's choice. Non-numerical qualitative data will be analyzed through an inductive process of grounded theory. Themes were identified through the constant-comparison method. Emerging themes were then coded. The results of analysis are reported via qualitative discussion without numerical summary. Research participants were provided with a Consent Form approved by the IRB.

#### **4.3 Interview Questions**

Some sample questions include:

1. How has cancer changed your way of life since being diagnosed?
2. Have people treated you differently because of your diagnosis?
3. What is something people can do—say, act, help—that can improve your situation?
4. Is it better for others to ignore the "elephant in the room" by not bringing it up, or would you rather they talk openly about it with you?

5. Do you feel your outlook on life has changed?
6. Are you surrounded by a support team or choosing a more private approach to fighting? If so, how are they helping you fight this disease?
7. Have the doctors/medical professionals made this ordeal easier on you and your family?
8. What kind of cancer were you diagnosed with? How old were you?
9. I want you to take me back to the beginning, bring me back to the moment when you first found out the news... Or were there symptoms before? What did you feel? What were you thinking? Paint me a picture.
10. How did you go about telling your friends and family?
11. The journey with cancer... What was that like? What was an average day for you? Were you able to be "normal" or did you feel different than the rest?
12. Can you tell me about your chemotherapy experience?
13. How do you feel about the words "cancer battle" or "fight"? Do you refer to it as a journey... Other words?
14. What helped you with cope with cancer?
15. What is one thing you would tell to other people out there going through this?
16. Do you know others out there with cancer at your age? If so, did you or would you connect with them?

#### **4.4 Collaboration**

By collaborating with Pelotonia's marketing/PR team, multiple OSU student organizations, and attending cancer awareness events in the Columbus area, such as Pelotonia, Relay For Life, and the Step Up for Stefanie 5k Run, I have gotten connected to young adult cancer survivors and enlisted their interest in sharing their stories of survival. The stories have reached more than 4,000 views on Facebook, with viewers commenting and sharing the quotes and photos conversations. I have used social media to network with people of similar interests, and to connect with existing cancer support communities. On Twitter, there is an impressive amount of cancer survivors, advocates, doctors, and nurses who post regularly on the topic of cancer. It has been an imperative part of my project to stay updated with articles, stories, and events that are posted. Importantly, I partnered with Camp Kesem, a student organization at OSU, and Stupid Cancer, a national youth cancer nonprofit which provides online resources, to help share the stories/photos I document. The two partnerships have helped me expand my network and reach a larger audience. The Twitter, Tumblr, and Facebook will be linked together in order to have uniform information, but will feature special posts (different to each social media outlet) every month.

The layout for the Facebook page is user-friendly and organized by date of post (most recent at the top). I was the only one uploading content to the social media sites, but anyone was able to comment. There were main posts, with photographs and stories from the cancer survivors, as well as posts of inspirational quotes, quotes from family members, controversial questions, and updates of Pelotonia. I wanted to encourage conversations on the topic of cancer so I have posed questions.

Pelotonia/The James can use the Twitter, Facebook, and Tumblr feeds to select certain stories to promote on their own respective sites. Also, the photos and interviews

can be used on banners and flags to be used as promotion and marketing. A specific example is to have each floor of The James be designated to the story of one survivor, which can rotate survivor stories or stay the same based on preferences. Their sayings and inspirational pictures can be posted on the floor in areas where they be induced as motivation for others. One other specific example is to have survivors and their stories to be used as marketing of Pelotonia, in addition to having pictures of those riding for their loved ones. Having the ability to see how the money is changing lives can cause more people to feel emotionally involved to partake in the race and its efforts.

This project has lasted for one year, but I am looking for someone who can pick up where I leave off and continue finding survivors to interview. If I can find the right team of motivated individuals, in the future, this project can be divided up by several people to collect more stories and have more information being pushed out from the social media sites.

<https://twitter.com/StrongerOSU>

<https://www.facebook.com/StrongerOSU>

<http://StrongerOSU.tumblr.com/>

#### **4.5 Consent Process of Participants**

Once potential research participants have contacted the researchers via e-mail or phone, the following procedures will be enacted:

- A. The researcher will meet with the potential research participant at a location of the potential participant's choosing.
- B. The researcher will read the Participant Recruitment Script [see attached] aloud to the potential participant. Simultaneously, the potential research participant will

have a written statement to read with precisely the same text.

C. The researcher will ask the potential participant if he/she has questions or requires any clarification concerning the project and/or what is required of them through the project.

D. The researcher will inform the potential participant that they will be given one full week (7 days) as a waiting period to consider participation. After the expiration of the waiting period, the potential participant will contact the researcher via e-mail or phone with a “yes” or “no”.

E. If the potential participant responds affirmative to participating in the project, the researcher will meet the participant at a location of the participant’s choosing.

F. At that meeting, the participant will be given a hard copy of the consent form.

G. The researcher will read the form to the participant and ask whether the participant has any questions about the consent form and the research intent and process as a whole.

H. Once the participant understands the form and is ready to sign up for the project, he/she will sign the form.

I. The researcher will accept the form and store it in a secure location.

Participants are all over the age of 18. Participants can choose to remain anonymous, that is, to keep their name confidential as participants in the study. If they choose to remain anonymous, that is, if they choose to keep their name confidential, their interviews will be given code numbers. The code numbers will be kept in a secure, locked cabinet on the OSU campus. Only the principal investigators will be able to connect the code number with the research participant. Research participants may also choose not to remain anonymous in the study. Participants may choose to have their

photograph taken or not. In reference to education level, the consent form and recruitment text will be written at a middle school grade level, clear, clean, concise.

Potential participants will be informed verbally and in writing that their participation is wholly voluntary. They may choose to keep their names confidential or allow the researcher to reveal their names in relation to their commentary. They may choose to have their photograph included in the study or not. In reading and studying the Consent Form with the researcher, they will learn that there are no tangible rewards for participating, nor are there any possible negative consequences, either for participating or for declining to participate. If the potential participant does not want to participate, the recruitment conversation will be immediately terminated.

## Chapter 6

### RESULTS

#### a. Interview 1



"I guess I didn't understand what cancer was, and I just thought it was a sickness that you just get over. A lot of other people just think, cancer - you die. Well, I kind of saw it as 'Oh it's getting better. They are finding cures to this kind of stuff' so I thought 'Whatever, just go with the flow, and they'll fix it'."

## b. Interview 2



“Being treated at an adult cancer hospital certainly impacted my journey because I didn’t have that team of people there realizing that I was a kid. There weren’t puppy dogs painted on the walls; there weren’t suckers when you did a good job, so you had to grow up quick. My mom was my advocate because people didn’t know how to listen to a 14-year-old kid in the hospital. Doctors use words that- I still remember ‘Are you feeling fatigue?’ I didn’t know what the hell ‘fatigue’ was, so I would say no. And mind you, I was sleeping 22 hours a day, OF COURSE I’m feeling fatigue. ‘Um, are you feeling fatigue?’ and I would say no because I didn’t know what that word was, and my mom would have to explain to them and to me, and be a cross-interpreter.”



**c. Interview 3**



“Having hope or something to hold on to is the biggest thing for those just diagnosed. Have a positive outlook and know that you will be stronger from it. It’s hard to look at the positives, but it will make you that much stronger. Just don’t give up. Everything happens for a reason.”

#### d. Interview 4



“I always have the thought in the back of my head that it’s gonna come back, which is not good. I have a friend of mine that’s a doctor, and I talk about this with my doctor too, and he’s like ‘You’re good, you caught it early’ but you still obviously never know. I do not take life for granted. I do look at things a little differently. I’ve always been sentimental, but I’m much more sentimental now, in terms of having family here for certain things.”

**e. Interview 5**



“For me, it was really important to participate, and not let cancer take over everything. I still wanted to be able to go to school. I was really into being able to go to the games, and I even cheered most of the games; I think I missed 2 or 3 games when I was sick. I wanted to be able to live my senior year, I wasn't going to let cancer stop me from doing that. Last day of school, I went to prom, and then we went on a senior trip and stayed there Sunday night, and Monday my dad came to pick me up at 4:30 in the morning. I took my last 3 days of chemo, got off Wednesday, and came back to school Thursday for my last day of school. Sometimes it was a lot, but you really just learn to deal with it.”

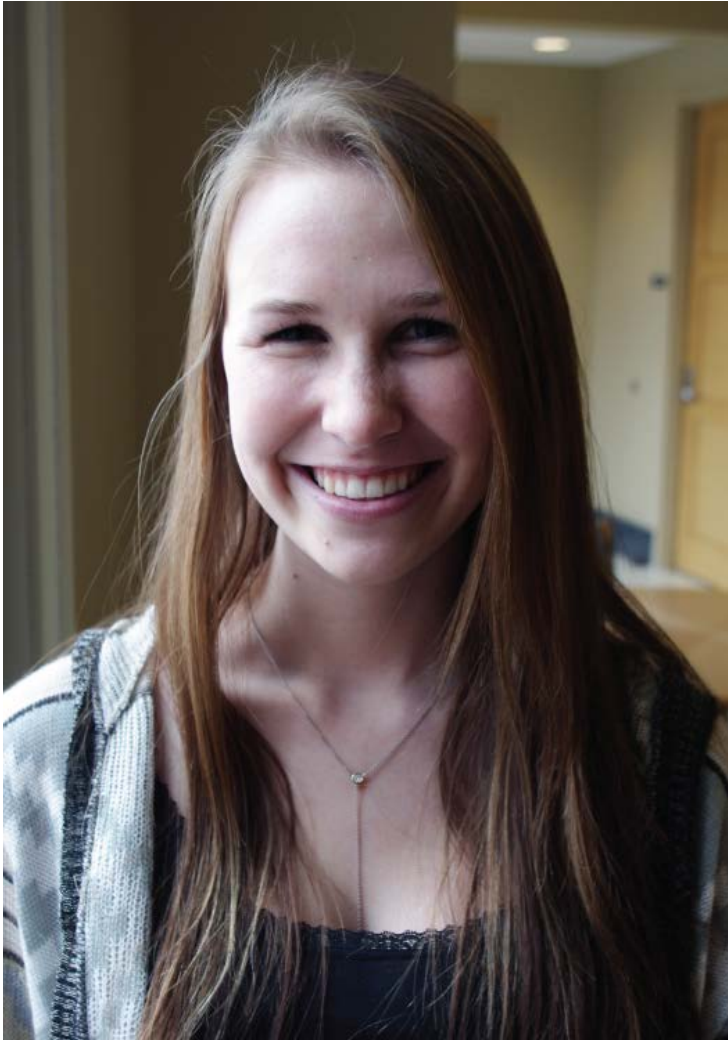
**f. Interview 6**



“It’s so interesting, the lingo that we use... ‘cancer survivors’, we’re ‘fighters’, we’re ‘battling’. I don’t know, in one way I get it, but in another way, I feel like I don’t do a whole lot; I’m just going to chemo and just sitting and receiving chemotherapy. I don’t feel like I’m ‘battling’ something, it’s not something I can actively see and actively do. If I could physically, fight cancer, or do something on my own, I totally would. There’s nothing I would want to do more, but I do feel like, I’ve been realizing and reflecting, that is more like a battlefield, or a fight, that I have in my brain, about what’s going on. So for me, it’s mostly when I think of the battle, it’s not the cancer per say, but of my mind. It’s the best way to describe it - that I’m always fighting against me in the moment, acknowledging it, not being in denial, because you can definitely do that; I sometimes do that, but being aware and willing to move forward and see past that...



**g. Interview 7**



“What is something that people can do to help current cancer patients?”

“I never wanted special treatment from people. So I think just treat them as normally as they can and don’t always talk about it while they’re going through treatment. You want to talk about other things and just kind of push that to the side for a little bit. We know they are there for us. They try to help, but going through treatment takes away your sense of independence. So you need them there for simple tasks that you did before, and they help you with that, in little ways. But then again you don’t want them to smother you and make you so dependent on them.”

## **h. Interview 8**



“I was really depressed in the beginning but eventually you find a new normal. My normal, when I was a kid and early teen, was being the best kid in gym class and the runner; not to brag, but I was pretty athletically inclined, so that was my normal. And then I had to come to the realization that sports aren’t what defined me, but it was hard, because that’s what I loved the most. So I just had to find other interests and other qualities about myself that I could be proud of. You just have to find a new normal; there’s no way to get around having a struggle, it’s just a matter of getting through to the other side, and feeling like you are still worth something.”

**i. Interview 9**



“There’s always questioning. I never doubted God’s existence, but I did question and seek to understand; I was curious. I will say, I think that was something that God really kept me from on his part, of keeping my mind from the ‘why me?’ I’m a super logical person, and so I knew heading in, right when I was diagnosed, the very first night I processed this on my own, I said to myself ‘I cannot go down this road, because this path leads to destruction and there is no end’. And so I think that was super healthy, and the Lord used my logic and reason-based understanding of what brings good and what brings evil to keep me from those things. My faith grew, and has grown, and is foundationally supported by my experience with cancer.”

## **Chapter 7**

### **DISCUSSION**

When talking to the 9 young adult cancer survivors, there were many common themes that arose. I found that it was vital to have a support group (friends/family), which helped them keep a positive mindset. The ‘support team’ mainly consisted of family and friends, but the doctors and nurses were also included. Small acts of care allowed for their cancer journey to be more light-hearted. Although most of them did not have a formal support group to attend, they felt cared for by their friends and family. One cancer survivor was 14 years old and was encouraged to attend the support group for the type of cancer she had; this was not successful because she had a type of cancer that was common in 70-year-old men. She had nothing in common with the men in this support group. What she needed were peers her age that she could converse with about what it’s like being young and having cancer. It is evident that medicine is the main focus for the ‘cure for cancer’, however, support is undermined and is a crucial component in the cancer journey. The patient cannot take care of themselves; sometimes they are too weak to drive or cannot do simple tasks such as going to the bathroom on their own if they recently got surgery. The participants that were not in a cancer survivorship support group said that they wished they had a support group of other cancer patients similar to their age during treatment. This common theme of support seemed to be a big factor of what allowed them to keep a positive mindset.

The supporters were always so positive, and accepted that whatever they needed to do in order to heal the cancer patient was to accept life as the ‘new normal’. This phrase of the ‘new normal’ was said in two interviews. It has a sense of peace and



acceptance, with no mention of complaining. Accepting the cancer journey as the ‘new normal’ allowed for the patient and his/her parents to not get depressed about the situation; they simply saw cancer like any other obstacle in life, and had to complete the necessary tasks in order to “beat cancer”.

Many cancer survivors found new hobbies and interests to keep their mind off of cancer. A couple of them were told ‘you cannot play sports anymore’ which caused them to have to find new ways to fill their time/energy. Some had to accept the fact that their body would never be the same after going through treatment and that their lifestyle would need to change.

Having good relationships and communication with doctors and nurses made their journey easier. The doctors and nurses have so much compassion and had created such close bonds with the cancer patients that it was repeatedly noted (during interviews) that they were an essential to their cancer healing. Some survivors are close enough to their nurses, that they will text them if they have questions about scans, or any worries they have concerning their health. The cancer survivors fully trust their doctors and nurses; when I asked if they ever questioned the doctor’s decision (of getting surgery, radiation, and/or chemotherapy), they said no.

For supporters, asking questions is a way to show care. Questions like “Do you need me to help with anything?” or “Do you need some space?” allowed the cancer patient to be able to communicate their needs, or politely reject the help. One survivor said that she did not like all of the presents and food, because it was overwhelming for her to constantly be the center of attention. She never spoke up, because she acknowledged that people wanted to express their care, but at her young age, she didn’t want so much attention.

In addition, there were some cancer survivors who mentioned how mentally

exhausting it was to have to constantly keep people updated. Some felt drained by having to report to the supporters, since they had people praying for them. For one cancer survivor, the journey really allowed for her to re-evaluate her friendships. She developed stronger bonds with friends that she never would have thought would be there for her, and on the other hand, had a friend who completely stopped being a friend. She said “it was easy to see who my true friends were”, and the experience influenced her to reflect on her friendships.

## **Chapter 8**

### **LIMITATIONS & CONCLUSION**

In difficult times during cancer diagnosis and treatment, family and close friends often do not know how to interact with and support the cancer patient. This project benefits friends and family of newly diagnosed patients, so that they might be more fully and sensitively supportive without the fear of saying or doing something wrong. The stories and photographs of young adult cancer survivors have allowed for cancer to not be such a 'taboo' subject. A cancer survivor who came across the Facebook page reached out to me to participate in my project and said, "I love the idea of your project. I just want to thank you for even thinking about doing it. You are right that no one likes to talk about it. Being back at school, I see that every day. So thanks for talking about it." Although cancer may be widespread, we as a community are not talking about it. We are not educated on the topic, which makes it hard to support those that are going through the cancer journey. It's even harder for the young adult cancer patients who are currently going through it, since they do not have a peer group to feel supported by. Surprisingly, young adult cancer patients/survivors are very open to sharing their story; they just don't get a platform to do so. Their experiences are all so different and some do not want to be identified as a 'cancer survivor' because they don't think their cancer experience completely defines who they are.

A mom of a young adult cancer survivor messaged me when my Facebook page first started, and said "I'm commenting to you on behalf of some of the older kids at Children's hospital that are or have been treated for cancer. They are college age and older. They are getting together October 11th at the Lynd's Fruit Farm in Alexandria. If

you would like to join the group I'm sure they would love to have you. My son attends OSU now and just finished his treatment. It's really a hard thing to go through so to have people who actually know what you're going through really helps you in this journey. Thanks for what you're doing." It was emotionally touching for a stranger to reach out and send this message. She saw the power of connection and wanted me to meet some cancer survivors in a relaxed environment. Although I was not able to go on the outing, a lot of the survivors that I interviewed told me the importance of the AYA cancer survivorship group. I learned that peer-to-peer relationships allowed for them to talk about their experiences, problems, and connect on a deeper level. The doctors and nurses who created the program and take the time to be a part of the group show the cancer survivors that they truly care.

This project was limited by the time and formality of the interviews. Although the environment was comfortable, there was paperwork to be signed, there were pre-set questions, and the participant was aware that they were being audio-recorded. In order to get more details, I would need to have more conversations/an ongoing dialogue, so that trust could be developed and more could be shared. In addition, organic conversations may have resulted in a richer story, but there are so many aspects of the cancer journey that we did not have time to explore.

Future exploration in relation to this topic can be researched, applying the same methods to people who have experienced different illnesses/traumatic events. For example, interviewing young adults who have experienced depression may be a way to bring light to the negative stereotypes and allow for people to have a better understanding of what depression is.

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## **APPENDICES**

## A. EMAIL TO STUDENT EXECUTIVE BOARDS

### Email to Executive Board of Ohio State University student organizations:

My name is Heidi Liou and I am a senior at The Ohio State University. I am beginning my senior thesis project which will be comprised of narrative research with photo-documentary of young adult cancer survivors. The project is titled *Stronger Than Ever: A Narrative and Photographic Project of Young Adult Cancer Survivors in the Columbus, Ohio Community*. I am being mentored throughout this project by Professor Candace J. Stout, Department of Arts Administration, Education, & Policy. I am seeking students who are cancer survivors, ages 18-35, who might volunteer to be interviewed. The central objective is to elicit their narratives, that is, their personal stories of their experiences in recovering from cancer. Interviews are interactive, conversational and open-ended, eliciting perspectives and experiences of recovery that participants volunteer to offer.

#### Sample questions are as follows:

- a. Who were the key individuals who comprised their support group?
- b. What was the nature of the support, the comfort, encouragement, reinforcement that these cancer survivors most desired and needed and did they receive this kind of support?
- c. How did those people comprising the support group best provide the support that the individuals wanted and needed?
- d. Outside of medical procedures and physical therapy, what was it that bolstered participants' spirits? What did they do to stay positive?
- e. What kinds of efforts from the support group were not helpful in the process of recovery?
- f. What are some of the most important things that the members of a cancer survivor's support group should know?
- g. What is the foremost piece of advice that participants would tell other people who are going through cancer recovery?

I would appreciate any assistance that you might provide in locating volunteers for my study. It would be especially helpful if I could attend one of your Executive Board meetings in order to speak in more detail and to answer questions about my project. I look forward to hearing from you.

Sincerely,  
Heidi Liou  
[Liou.Heidi@gmail.com](mailto:Liou.Heidi@gmail.com)



## **B. INTERVIEW RECRUITMENT SCRIPT**

Hello (name),

My name is Heidi Liou and I am a senior currently working on my senior thesis entitled "Stronger Than Ever", with mentor Dr. Candace Stout. I would like to tell you about a narrative study that we are conducting. We are interested in the recovery experiences of young adult cancer survivors in the Columbus Community. The purpose of our study is to gather and share the stories of young adult cancer survivors during their time of recuperation from cancer. We are interested in how those people who made up your support group encouraged and supported you during your recovery. Outside of medical procedures and physical therapy, from your experience, how did you stay positive? What are some of the most important things that those around you, ranging from family, friends, care-givers, did for you? What would you like to tell other people out there who are going through cancer recovery? Our study consists of a one-hour interview in the location of your choice.

We are asking you to participate in this study because we think you have some important insights and advice to offer readers who, through choice or necessity, might one day need to provide support for those undergoing cancer treatment. In addition, we are interested in your insights because they may help others who are undergoing cancer treatment themselves.

Participation is strictly voluntary. If you choose to participate, you may choose to use your own name or create a "pen" name, that is, create a pseudonym. You may choose to have your photograph taken for the project or not. I am happy to answer any questions that you may have before you choose to participate or not to participate. Attached is the letter of consent that talks about my project more in detail (no need to do anything with it). Thank you.

Sincerely,

Candace J. Stout, Professor Arts Administration, Education & Policy

Heidi Liou, Undergraduate Student, College of Education and Human Ecology

## **C. INTERVIEW SCRIPT**

### **Pelotonia Interview Questions**

- 1) What is your full name, age?
- 2) Can you tell me a little about yourself?
- 3) What kind of cancer were you diagnosed with? How old were you?
- 4) I want you to take me back to the beginning, bring me back to the moment when you first found out the news...
  - a) Or were there symptoms before? What did you feel? What were you thinking?  
Paint me a picture.
- 5) How did you go about telling your friends and family?
- 6) The journey with cancer... What was that like?
  - a) What was an average day for you? Were you able to be "normal" or did you feel different than the rest?
- 7) This might be a sensitive subject but can you tell me about chemotherapy?
- 8) How do you feel about the words "cancer battle" or "fight"?
  - a) Do you refer to it as a journey... Other words?
- 9) How has cancer changed your way of life since being diagnosed?
- 10) "Did you change anything about your lifestyle after you were diagnosed?"
- 11) Have people treated you differently because of your diagnosis?
- 12) What is something people can do—say, act, help—that can improve your situation?
- 13) Is it better for others to ignore the “elephant in the room” by not bringing it up, or would you rather they talk openly about it with you?
- 14) Do you feel your outlook on life has changed?
- 15) Are you surrounded by a support team or choosing a more private approach to fighting?
  - a) If so, how are they helping you fight this disease?
- 16) Have the doctors/medical professionals made the journey easier on you and your family?
- 17) "What helped you with cope with cancer?"
- 18) "What is one thing you would tell to other people out there going through this?"
- 19) "Do you know others out there with cancer at your age? If so, did you or would you connect with them?"

## D. IRB APPROVAL



### Behavioral and Social Sciences Institutional Review Board

Office of Responsible Research Practices  
300 Research Administration Building  
1960 Kenny Road  
Columbus, OH 43210-1063

Phone (614) 688-8457  
Fax (614) 688-0366  
[www.orrp.osu.edu](http://www.orrp.osu.edu)

December 8, 2014

Protocol Number: 2014B0515  
Protocol Title: STRONGER THAN EVER: A NARRATIVE AND PHOTOGRAPHIC PROJECT OF YOUNG ADULT CANCER SURVIVORS IN THE COLUMBUS, OHIO COMMUNITY, Candace Stout, Heidi Liou, Art Education  
Type of Review: Initial Review—Expedited  
IRB Staff Contact: Jacob R. Stoddard  
Phone: 614-292-0526  
Email: [stoddard.13@osu.edu](mailto:stoddard.13@osu.edu)

Dear Dr. Stout,

The Behavioral and Social Sciences IRB **APPROVED BY EXPEDITED REVIEW** the above referenced research. The Board was able to provide expedited approval under 45 CFR 46.110(b)(1) because the research meets the applicability criteria and one or more categories of research eligible for expedited review, as indicated below.

Date of IRB Approval: December 8, 2014  
Date of IRB Approval Expiration: December 8, 2015  
Expedited Review Category: 6, 7

If applicable, informed consent (and HIPAA research authorization) must be obtained from subjects or their legally authorized representatives and documented prior to research involvement. The IRB-approved consent form and process must be used. Changes in the research (e.g., recruitment procedures, advertisements, enrollment numbers, etc.) or informed consent process must be approved by the IRB before they are implemented (except where necessary to eliminate apparent immediate hazards to subjects).

This approval is valid for **one year** from the date of IRB review when approval is granted or modifications are required. The approval will no longer be in effect on the date listed above as the IRB expiration date. A Continuing Review application must be approved within this interval to avoid expiration of IRB approval and cessation of all research activities. A final report must be provided to the IRB and all records relating to the research (including signed consent forms) must be retained and available for audit for at least 3 years after the research has ended.

It is the responsibility of all investigators and research staff to promptly report to the IRB any serious, unexpected and related adverse events and potential unanticipated problems involving risks to subjects or others.

This approval is issued under The Ohio State University's OHRP Federalwide Assurance #00006378. All forms and procedures can be found on the ORRP website – [www.orrp.osu.edu](http://www.orrp.osu.edu). Please feel free to contact the IRB staff contact listed above with any questions or concerns.

Michael Edwards, PhD, Chair  
Behavioral and Social Sciences Institutional Review Board



## **E. PHOTO RELEASE FORM**

### **Authorization/Consent for Interview, Photography and/or Video Release of Information**

April 2014

Heidi Liou Senior Thesis 2014-2015: Stronger Than Ever

#### **For release of photo/image:**

I, \_\_\_\_\_, voluntarily give my permission to Heidi Liou for my image, voice or both, to be recorded, published and/or distributed for news, educational, marketing or publicity purposes. I understand that once this protected information is printed, recorded and/or electronically posted, Heidi Liou retains no further control over its use.

#### **For release of medical information:**

I, \_\_\_\_\_, voluntarily give my permission for protected medical information regarding my medical condition or treatment to be released for news, educational, marketing or publicity purposes. I understand that once information is printed, recorded and/or electronically posted, Heidi Liou retains no further control over its use.

I confirm that I am 18 years of age or older and understand that by signing this form my information may no longer be protected by federal privacy rules or other confidentiality measures. I have been offered the opportunity to ask questions, or have this form read to me. I understand that I may revoke this authorization, in writing, at any time to Heidi Liou. Any revocation will not apply to information that has already been released, printed, recorded and/or electronically posted. I also understand I am not required to sign this form as a condition of treatment, nor do I expect financial remuneration for the use of my image or medical information.

This authorization will expire: \_\_\_\_\_.  
(Date or specific event)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

Mailing Address \_\_\_\_\_

Daytime Phone Number \_\_\_\_\_

Participant (check one): ☐ patient ☐ faculty/staff ☐ other